

Voices from the Margins: Reflections of an Oncology Chaplain

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I serve as the oncology chaplain for the Simms-Mann/UCLA Center for Integrative Oncology. My journey here has been somewhat unusual, in that I am neither an ordained minister, nor particularly religious in any conventional way. What might at first read like a disjointed resume, from where I stand now, mine looks instead like a more accurate depiction of life—as it is. Twists, turns, sudden drops, unexpected detours that lead to new places we never could have anticipated and certainly never aimed for. And along the way, crisis, sometimes devastation... and sometimes redemption and profound healing. A new understanding of who we are and what life is, what it all means. From what I've observed, that is an image of the cancer journey as well.

As a young man, I began a 10-year career as a free-lance professional dancer. Years of auditions, and far more rejection than acceptance gave me a bone deep understanding of that feeling that, "I've done my best, and yet no matter what I do, it's just not enough. I'm not enough. I'm not the one who was chosen." I then made a sharp pivot turn toward a 20 year career as a self-employed interior designer/architect. Life doesn't always let us choose to which music we will dance, or when we will lead and when we must follow. I truly felt led to volunteering for a fledgling AIDS hospice project in Los Angeles in 1991. This was a whole new dance, and it sparked the beginning of the journey that led me to chaplaincy and to UCLA these many years later.

My supportive role in this tragic dance in the early, terrifying days of the AIDS pandemic, demanded that I learn to come to peace with death and unanswerable questions in a whole new way, all the while holding the space open for more exploration of what it all means. It also demanded creating a safe and sacred place for those, even closer to the edge, to tell me their stories. These are hallmarks of my work as I see it. I like to think that I speak from the place where all of us find ourselves at one time or another-- in the place of the outsider, in the margins... misunderstood, isolated, abandoned, perhaps doubting long held beliefs, and now holding more questions than answers.

My own experience as the outsider, speaking from the margins, has its deepest roots in my journey growing up somewhat invisibly as a gay child, coming into adulthood by way of the pain of the closet. The journey inspired a passion

to co-create and to serve as chair of a non-profit, volunteer anti-homophobia speakers bureau in Los Angeles called GLIDE, Gays and Lesbians Initiating Dialogue for Equality. Over the last 20 years, my fellow speakers and I have spoken to an audience of nearly 200,000 students, teachers, and other various groups and agencies in the LA area about homophobia. I see both pursuits, this and chaplaincy, as closely related in that both fields have to do with creating nurturing spaces for people to fully tell their truths and to be received with respect—and love.

In a way, I feel uniquely qualified to walk beside those who face a cancer diagnosis, a life turned upside down and perhaps cut short. The questions they ask of God or the Divine, are familiar questions to one who has been asking those questions since boyhood-- *"Why did this happen?" "Am I outside of God's grace?" "Why can't I just live my life like everyone else?" "Doesn't God love me?" "Am I even entitled to love and be loved?"*

The shared experience of passing these stories around the expanding circle of listeners and speakers continues to connect these two lifetime commitments, chaplaincy and my work with GLIDE with its healing power. These stories have become a part of me, and a part of my voice, giving me the authority to claim my own space in the dance and hold space for others. I have learned that the most profound changes happen within the listener's spirit. It is much easier to hate an idea than a human being embodying that idea, who is standing right in front of you. I have witnessed hate and fear melting under these encounters, countless times—hearts opening up and communion taking place there in an inner city high school classroom.

In my work as an oncology chaplain, I have been privileged to witness this transformative communion happen in an infusion clinic with a patient, a different kind of classroom, with the roles reversed. In the clinic, I see my role as that of the student and the patient as the teacher... teaching me what it is like to be them. Let me be clear. I don't have cancer. It would seem arrogant and presumptuous of me to tell them how they need to be, how they need to think, what they need to believe. Oddly enough, putting the patient in that role as the teacher can be an empowering gift, when cancer has robbed them of so much. It is not only I who is being

taught—the patient is teaching himself as well... reminding himself just who is, what he's made of, what he's connected to.

With the perspective of having been witness to thousands of patients on their journeys through crisis, I can often affirm the legitimacy, if you will, of each patient's journey, her experience or her new discovery of "truth" or meaning. Many patients will ask something like, *"Have you ever known any other patients to go through this?"* When I can answer, *"Why yes, I just spoke to a woman last week who felt the same way,"* it can be a soothing balm indeed—a small piece of normalcy in a world so suddenly changed forever. Receiving stories. Giving back stories.

My work with GLIDE in combination with my chaplaincy, planted a seed ten years ago that grew into another opportunity to connect—speaking publically to a larger audience about my work as a chaplain and the life lessons I've found there. When I began my CPE internship at UCLA in 2000, I had of course explained in my application materials and interview that I was not a conventionally religious person, even somewhat hostile to institutionalized religion. Nevertheless, I was accepted and then told I needed to align with a recognized religious community! The Unitarian Universalist Community Church of Santa Monica was a good fit for me and became a spiritual home. In preparing for the Coming Out Day Sunday service in 2004, I volunteered to give the sermon. I called it, *"Coming Out: It's Everybody's Business,"* exploring how it is that coming out is something we all do every time we dare to risk sharing our truth.

That talk was very well-received and has led to an annual invitation to speak at my home church and, as it turns out, to an ever-increasing audience. I've been invited many times to speak to students, doctors, nurses, social workers, and to dozens of faith communities across the country. I recently presented at the National Conference for Young Women Affected by Breast Cancer in Orlando, and was the keynote speaker at the Promising Practices for Mental Health and Aging Conference at the California Endowment. Last April, I gave the keynote at the 2015 National Conference for Women Living with Metastatic Breast Cancer in Philadelphia. In early 2014 I was thrilled to be invited to do a TED-X talk which is available on YouTube.

Last year I wrote a talk called, *"Restraining the Beads,"* exploring how we sometimes use our stories to make spiritual sense of our lives. I've given that sermon now, perhaps a

dozen times or more this year. It's a deeply personal talk and can take me to deep places each time I give it. I find it resonates profoundly with others despite the specificity of its meaning to me. One woman at a congregation in Southern California came up to me after the service and said, *"I'm not sure if I'm crying for your stories or for my own—and I wonder if it matters."* For me, that's it-- right there. Does it matter? I would say what matters is the compassion, the communion beyond the story.

The Simms/Mann-UCLA Center for Integrative Oncology has had a 20-year history of providing monthly lectures at UCLA, geared toward cancer patients and loved ones, free of charge and open to the public. The talks are videotaped and available for viewing on-line at the Simms/Mann website. My most recent lecture is called *"Cancer: 'It Could Be Worse'—A Spiritual Ponzi Scheme?"* The talk explores a common coping strategy used throughout the larger circles of life, but especially within the world of cancer, by both patients and caregivers alike — *"it could be worse."* Embracing that frame of mind is often presumed to snap those struggling back into *"an attitude of gratitude,"* so the burden doesn't seem so heavy. As one contemplates the universe or even one's understanding of God, *"it could be worse"* might seem to balance out one's perception of the scales of justice and fairness. But what are the implications? What does it say about our view of suffering and the suffering of others? What is the cost of clinging to *"it could be worse,"* as a way of getting through our challenges? I do not have the answers to these questions, but I have found a doorway that invites us all inside to explore them. I love how Barry Lopez puts it: *"Everything is held together with stories. That is all that is holding us together, stories and compassion."*

A few years ago I was giving a talk to the Cancer Support Community, and during the Q&A, a woman living with cancer asked me about *"the meaning of life."* She didn't really want an answer from me, (as if I had one) but she wanted to share her discovery of truth. In her view the meaning of life was *to be known, to be seen--* that everyone, deep down, wants to be known... not as in *"to be famous,"* but to have been seen, witnessed, received as we are and as we are not. The more I think about it, I believe there is a profound truth there. Perhaps our spiritual quest, our role as healers is to discover and know the other—and our doorway, our invitation into the dance, might be the story... listening and giving it back.

(See: <http://www.simmsmanncenter.ucla.edu/?p=2190>)

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